

Forsyth R, Young D, Kelly G, Davis K, Dunford C,
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[Paediatric Rehabilitation Ingredients Measure: a new tool for identifying
paediatric neurorehabilitation content.](#)

Developmental Medicine and Child Neurology (2017)

DOI: <https://doi.org/10.1111/dmcn.13648>

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Date deposited:

19/12/2017

Embargo release date:

21 December 2018

A Paediatric Rehabilitation Ingredients Measure (PRISM) for identification of paediatric neurorehabilitation content

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3335 Words

2 Figures (+ 1 supplementary figure)

2 Tables

Abstract

Purpose: to develop an instrument (Paediatric Rehabilitation Ingredients Measure, PRISM) for quantitative estimation of contents of interdisciplinary neurorehabilitation for use in studies of relationships between rehabilitation treatment delivered and severity-adjusted outcomes after acquired brain injury.

Materials and methods: The measure was developed using an ingredients-mediators-outcomes model consistent with the International Classification of Functioning, a literature review, and other current initiatives in the development of rehabilitation treatment taxonomies, with item co-development in workshops with rehabilitation professionals. Inter-rater reliability was assessed in inpatient and residential paediatric rehabilitation settings.

Results: Although sometimes an initially-unfamiliar perspective on rehabilitation practice, PRISM's acceptability amongst professionals was excellent. Internal consistency of scores was sometimes an issue for users unfamiliar with the tool however this improved with practice and inter-rater reliability (assessed by Kendall W) was good. The tool was felt to have particular value in facilitating inter-disciplinary communication and working. Modifications to the design of the tool have improved internal consistency.

Conclusion: PRISM supports identification of the "active ingredients" of an interdisciplinary rehabilitation package and facilitates interdisciplinary communication. It also has potential as a research tool examining relationships between rehabilitation delivered and severity-adjusted outcomes observed after paediatric acquired brain injury.

What this paper adds

- Trying to identify the contribution of rehabilitation to outcomes after Acquired Brain Injury (ABI) requires approaches for the quantification of rehabilitation “dose” and “content”.
- Previous approaches to the “parsing” of rehabilitation dose and content may have over-emphasised 1:1 contact sessions with therapists
- We present a novel, holistic tool for the identification of the ingredients of an interdisciplinary rehabilitation package. It supports interdisciplinary communication; and has potential as a research tool.

Introduction

Acquired brain injury (ABI) is a growing problem for paediatric health services as survival rates after severe illness improve¹. A degree of recovery of function is typically seen in the weeks and months after ABI, although the extent to which neurorehabilitation efforts are responsible for this is disputed². One of the difficulties in addressing this as a research question is the lack of validated methods for characterisation of the “dose” and “ingredients” of the rehabilitation delivered, which is a pre-requisite for any study of quantitative relationships between rehabilitation treatment received and severity-adjusted outcome. Although not without their own challenges, theoretical frameworks and methodologies exist for assessment of outcome after ABI^{3,4}, and for detection of differences between observed and expected severity-adjusted outcomes⁵. In contrast, approaches to the quantitation of rehabilitation input are much less well-developed.

Previous efforts in this area have largely been in the context of adult stroke and traumatic brain injury (TBI). The Post-stroke Observation Project (PSOP)⁶ and the Collaborative Evaluation of Rehabilitation in Stroke across Europe project (CERISE)⁷ were both multi-centre comparisons of rehabilitation delivered and outcomes achieved after adult stroke. Both focussed on the content of therapy sessions on a closely observed, minute-to-minute basis using pre-defined observation schedules. Relationships between rehabilitation received and outcome appeared weak⁸. CERISE highlighted the need to take a broader view of therapists’ activity even in apparent direct contact time⁹. In a recent report Hart *et al*¹⁰ used a “natural experiment” design utilizing differences between US and Scandinavian health-care settings to seek dose-response relationships between rehabilitation and outcome after adult TBI. Rehabilitation delivered was captured under two broad headings: “functionally-oriented treatment” (total hours of physical, occupational, speech and related therapy) and “emotionally

oriented treatment” (total hours of social work, psychology and related therapy). Again no relationships between outcome and rehabilitation “dose” could be demonstrated.

It is possible that there *are* no dose-response relationships between rehabilitation received (however described) and outcome, at least at the level of body structure and function: i.e. whilst it has been shown that there are effective ways to improve participation by changing a child’s environmental context¹¹ our ability to change the child herself may be more limited. A more positive alternative is that relationships between rehabilitation and outcome may be demonstrable if dose and content are captured in an appropriate way. For example, PSOP captured the content of units of rehabilitation time in terms of items such as “dressing practice”, “balance training”, “postural awareness” and “prescription/selection of equipment”. It is perhaps unsurprising that there is no relationship between hours spent selecting equipment and functional gain, but a deeper issue could be that the wrong approach has been taken to the parsing of rehabilitation content. “Dressing practice” may be an inadequate description of the content of that unit of time. Two professionals’ rehabilitation sessions, each coded as “dressing practice”, might differ importantly in pertinent active ingredients as experienced by the patient. More generally, we regard *assumptions that rehabilitation content can be inferred from the targeted impairment* (e.g. “balance training”) as flawed: no one would consider it appropriate to consider bariatric surgery, calorie-restricted diets and exercise programmes together as interchangeable forms of “obesity therapy” (see also Discussion). Another important limitation of the PSROP and CERISE approaches is the emphasis on the content of face-to-face formal therapy sessions. Particularly in inpatient settings, the effects of the broader 24/7 “therapeutic environment” will be under-valued by such perspectives.

We hypothesise that quantitative relationships exist between severity-adjusted outcomes after paediatric ABI and rehabilitation delivered. Effective testing of this hypothesis requires optimised approaches to capture of rehabilitation input, requiring in turn theoretically-grounded views of “what rehabilitation is”. This paper describes the development of an instrument

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dubbed PRISM (Paediatric Rehabilitation IngredientS Measure, with its intended metaphor of splitting light into constituent colours). The envisaged clinical context for this instrument covers both early acute inpatient rehabilitation and community-delivered therapy. The former would typically comprise hours of direct contact with health professionals daily in a setting with a 24h “rehabilitation ethos”; the latter perhaps an hour a week or less with a single professional. Other characteristics of the intended clinical context include that interaction is usually individual rather than group work; with or without a parent present; and often interdisciplinary with professionals working together toward shared goals. It needs to be flexible enough to encompass different clinical scenarios, from the child with a severe disorder of consciousness (i.e. showing no awareness of her surroundings); to the child actively relearning motor skills; to a child back home trying to reintegrate socially and emotionally with school and family. Although the instrument is being developed in the context of paediatric neurorehabilitation we anticipate the approach can be adapted to suit wider rehabilitation settings and adult contexts (see Discussion).

The aim of PRISM is to develop a framework for the capture of action-mediator combinations in a broad, synoptic manner. The rationale is threefold. Firstly it would be very unusual clinical practice to use rehabilitation interventions in isolation. The same actions might be assisting a child to re-establish head control whilst at the same time aiming to improving mood and speech production (this is particularly the case for younger children where rehabilitation will often be delivered in the form of play). Secondly single ingredients (such as provision of feedback) are typically pertinent to multiple mediators and rehabilitation contexts. Thirdly, we require data that can be meaningfully compared across the range of clinical profiles seen in early rehabilitation (e.g. a child with hemiplegia working on upper limb skills; a severe disorder of consciousness; severe emotional and mental health barriers to rehabilitation; memory impairments) and that can be compared longitudinally throughout a child's rehabilitation journey as the goals and content of their treatment evolve.

Methods

Development of ingredient-mediator matrix

The first stage of PRISM development was to agree a structural (process) model defining the causal pathways and mediators by which rehabilitation ingredients might be hypothesised to affect outcomes. This development work is described in the Supplemental Material.

The resulting five row by four column table of potential ingredient-mediator combinations is shown in Table 1. Of the 20 possible ingredient-mediator combinations 9 were considered not applicable (indicated by “no” in Table 1): for example, the physical environment cannot be the literal recipient of an educational intervention (see Discussion), leaving a menu of 11 possible rehabilitation content-mediator combinations.

Application of Analytic Hierarchy Processing approach

We had as a design goal that PRISM should be amenable to analysis using the Analytic Hierarchy Process (AHP)^{12,13}. AHP is widely used in decision-support problems as it allows complex multi-way prioritisations to be considered as a series of pairwise comparisons. For a previous example of the use of AHP to “deconstruct” complex health interventions see Czaja *et al.*¹⁴. A simplified description of the AHP approach is illustrated in Figure 1. One important limitation of AHP is that the number of items n to be prioritised should be limited as the approach requires raters to consider every pairwise combination, which rapidly becomes onerous as n increases (6 comparisons for $n = 4$ items; 10 for five items; 15 for six, etc). However there are several advantages to the approach: it results in a simple vector of length n quantifying the relative proportions implicit in the pairwise comparisons, of the n “ingredients”. This is well suited to use in further quantitative analyses. It also provides an internal consistency check (if X has been rated as somewhat more important than Y, and Y than Z, then X should have been rated a lot more important than Z).

Using a custom-built web-based on-line system¹, raters were first asked to select items from the menu of 11 content-mediator combinations (Table 1) pertinent to the case being considered. They were reminded of the time-consuming nature of large- n ratings and encouraged only to select items they felt were truly relevant (typically 4-7 items). They were then presented with a screen showing all pairwise combinations of the n items they had selected at each end of a visual analogue scale with “slider” controls that they could move horizontally as shown in Figure 1A. Moving the slider to the extreme left indicates the rater feels the left-hand item is “extremely” more emphasised in the child’s current rehabilitation provision than the right-hand item and vice versa. Leaving the slider in the centre indicates the two items are equal in emphasis. On completion an internal consistency statistic was shown, although in the pilot version of the software no opportunity to return and adjust scores to improve consistency was provided (see Discussion). Finally raters were also asked to estimate total rehabilitation “dose” using an item adapted from the Rehabilitation Complexity Scale¹⁵ (Table 2).

The output from an AHP analysis is a vector (Figure 1C) containing the implicit proportions (adding to 1) of the n items from Table 1 considered pertinent by the rater in a given situation (the proportion of each of the menu items not selected is set at zero).

¹ Further details available upon request from corresponding author

Clinical evaluation and inter-rater reliability

After prototyping in Newcastle and Cambridge, an initial inter-rater reliability exercise was completed in Newcastle, where inpatient rehabilitation is delivered by a small team of professionals with high levels of joint working and informal interaction and discussion. Raters naïve to PRISM were shown an explanatory video introducing the Table 1 matrix and demonstrating an AHP rating exercise using the computer-aided system. They were then asked to perform AHP ratings blinded to others' scores.

A subsequent inter-rater reliability exercise was performed at The Children's Trust, Tadworth. This is a much larger service with large teams within each discipline. In this exercise, the Table 1 matrix items relevant to a child were agreed with treating teams at clinical meetings by LW, GK or KD, before treating clinicians independently rated the relative emphases of the pre-agreed items. Again, raters were blinded to others' scores.

Statistical analysis

The AHP algorithm was implemented and statistical analysis performed in R¹⁶. Non-parametric methods were used to analyse the AHP-derived rehabilitation content proportions. This is because (i) as proportions they are not fully independent of each other and (ii) the encouragement to raters to limit the number of ingredient items included in any rating means the data is zero-inflated. Inter-rater reliability was quantified using Kendall's W statistic¹⁷.

As an approach to recording and summarising clinical activity already routinely documented, with no consequences for or effects on patient care, this study was deemed service evaluation by standard criteria² and Research Ethics review was not sought. It was endorsed by The Children's Trust Research Committee.

² www.hra-decisiontools.org.uk

Results

Confirmation of ingredient-mediator matrix

See Supplemental Material for more information.

Clinical pilot studies

Whilst often an initially somewhat unfamiliar perspective, clinicians grasped the PRISM model and the principle of the AHP comparison approach readily. The main challenge in practice was the need to consider the whole-team perspective and visualise the “big picture” of the combined efforts of all members.

In initial Newcastle inter-rater reliability (IRR) exercises ($n = 3$, where raters were free to select relevant ingredient items independently and were entirely naïve to the AHP approach), consistency ratios (reflecting internal consistency within a rater’s rankings) ranged from 4-19% (median 13%). An example of a Newcastle child’s rating is shown in Figure 2, top left. Box-and-whisker plots show the range of proportions allocated by each of 7 raters amongst the available ingredients. The allocations reflect the clinical picture of a highly motivated teenager actively participating in motor relearning in the early weeks after a dense hemiplegia. Kendall W (reflecting inter-rater reliability) for Newcastle children ranged from 0.57 to 0.83.

In a subsequent IRR exercise at The Children’s Trust (TCT), six children were each rated five times by a total of 20 individuals. In this process, prior consensus was obtained amongst raters as to which ingredient items to use before ranking them. Again typical examples are shown in Figure 2, centre top and right. The prior consensus step greatly improved the IRR as assessed by Kendall W, with values from 0.92 to 0.99. Internal consistency ratios (again for largely AHP-naïve raters) ranged from 0% to 54% (median 17%, IQR 6-25%).

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Figure 2, bottom, shows “PRISM profiles” for the six TCT children. For each child the medians (across raters) of the proportions of each rehabilitation ingredient are shown.

Important and clinically meaningful distinctions emerge: for example active practice of skills is an important priority for case TCT1 but not for TCT2 or 3, both of whom have severe disorders of consciousness, are not able to command-follow and are thus unable to actively practice. For them “other management of body structure and function” are strong emphases.

Discussion

This paper describes the development of a pragmatic tool for the capture of the relative proportions of “ingredients” of delivered rehabilitation. We envisage clinicians researchers using PRISM perhaps every one to two weeks during early, active inpatient rehabilitation care (less frequently at later stages) to capture the evolving focus of the rehabilitation team’s efforts as rehabilitation progresses. Whilst we have developed the approach in the specific context of paediatric *neurorehabilitation* we believe it could be readily adapted to contexts including non-neurological (e.g. rheumatological) and adult rehabilitation with some modification of the rows and columns of Table 1.

Our current research context requires that we use PRISM to capture what is *actually* happening *now* (c.f. what should be happening, or what will be happening in due course): however, the approach could equally be used to help envisage future or alternative “therapy packages”. Indeed, one important and unanticipated benefit of the tool was that we found the discussion around the “ingredient selection” step greatly encouraged and facilitated interdisciplinary communication and working, particularly in the setting of the larger teams at TCT, by encouraging professionals to think synoptically about the “whole-team effect”. It also encouraged recognition and consideration of the rehabilitation potential of the whole 24h programme of care: e.g. the therapeutic value of nursing and care staff actions in the evenings and at weekends.

In this regard we again emphasise that our intended scope for PRISM is *limited to the actions of the professional rehabilitation team*. Many other dynamics are of great importance in the recovery of children after ABI (particularly the responses of the family¹⁸ and educational professionals¹⁹) but we consider the actions the *rehabilitation professionals take* to promote these have ingredients of emotional support and knowledge transfer to families; and knowledge transfer and advocacy with education professionals. We found some potential for ambiguity in

classifying interventions targeting the environment in terms of Table 1. For example some raters viewed recommending that a child move to a specialist school after ABI as “adapting the physical environment” whereas most viewed it as primarily an advocacy intervention (“adapting the attitudinal environment”), arguing for access to a pre-existing appropriate educational resource. In a research setting such issues require prior discussion and agreed approaches to ensure consistency.

Practicability has been an important design priority. The very detailed minute-by-minute observations of the PSROP and CERISE projects are too resource-intensive for our purposes, and impractical in a community setting. Furthermore, by concentrating on the detail of the content of formal 1:1 “therapy sessions” these approaches miss important dynamics outside those sessions and contributions of professionals often (erroneously) regarded as peripheral to the rehabilitation process such as care staff. We believe this broader perspective to be a unique strength of PRISM. This broader perspective is also important given the wide range of situations a pragmatic tool will need to cover illustrated to an extent by the range of PRISM profiles in Figure 2. Because these AHP scores are simple proportions, they can be added (e.g. to generate the aggregate rehabilitation efforts allocated to child *vs.* family *vs.* environment). By incorporating PRISM into a measurement model where the mediators of our process model (the column headings of Table 1) are independently measured, we can test a theoretically informed model of how rehabilitation ingredients affect ultimate outcome via which mediators.

It could be argued that AHP gives a spurious sense of precision to what are fundamentally intuitive, semi-quantitative judgements, but the inter-rater reliability data presented here is reassuring, in keeping with previous applications of AHP to the “decomposition” of complex health interventions¹⁴. The internal consistency ratio statistic was in some cases unacceptable (high ratios indicate inconsistencies between pairwise ratings: it is suggested that a consistency ratio <10% reflects an adequate rating¹²). Consistency comes with practice and improves rapidly with familiarity with the approach. The higher (poorer) ratios

were seen in individuals using the approach for the first time (Supplement: Figure 3). In an updated version of the on-line software we are providing raters with immediate feedback on mutually-inconsistent ratings and providing an opportunity for these to be adjusted in real time which has addressed this issue. Although we have created a bespoke AHP system for PRISM, generic AHP calculators (requiring manual entry of the selected menu items before the pairwise comparisons are performed) are widely available online and commercially.

An important limitation of the work described here is that AHP only defines the relative proportions of rehabilitation ingredients. AHP proportions need to be multiplied by a “dose” figure representing quantity. The appropriate dose quantifier for “active practice” rehabilitation is most obviously hours of contact time with professionals. It is less clear for example however that time (hours on the telephone?) is a useful quantifier of effort aiming to address physical barriers to participation in the environment. However estimates of doses of the less readily quantifiable aspects of input might be available using practice-rehabilitation as a “conversion rate”. For example: child A is in the acute inpatient phase of rehabilitation, receiving 14 hours per week of direct therapy focussing on active practice and with an overall package estimated by AHP to comprise 40% active practice of activities and functions and 10% mitigation of anticipated attitudinal barriers. Child B is in the community late after injury and her therapy is estimated by AHP as comprising 5% active practice and 70% promotion of attitudinal change. If it can be assumed that Child B's active practice relates entirely to an hour monthly of direct contact with her physiotherapist then in fact both children are receiving the same "dose" of attitudinal change input (3.5 "units" per week). This is an oversimplification but we are exploring this approach, using PRISM in combination with existing tools for the capture of use of professionals' time such as the Northwick Park Therapy Dependency tool ²⁰ and the Rehabilitation Complexity Scale (Table 2).

Acknowledgements

We are grateful to the rehabilitation professionals who took part in the PRISM development workshops and who participated in the inter-rater reliability exercises. We thank Niina Kolehmainen and John Whyte for helpful discussions.

This paper reports independent research funded by the National Institute for Health Research (NIHR) Programme Grants for Applied Research Programme Development Grant scheme (RP-DG-0613-10002) The views expressed are those of the authors and not necessarily those of the NHS, NIHR or the UK Department of Health. The funder played no role in study design, data collection, data analysis, manuscript preparation or publication decisions.

Legends to Tables and Figures

Tables

Table 1. Ingredients-Mediators matrix. For the relevance of the “yes” and “no” entries, see Methods. *Note that “adaptation of the physical environment” (third column of last row) was defined as environment outside the family home, which was treated separately as “adaptation supporting the family” (second column of the last row).

Figures

Figure 1. Illustration of Analytic Hierarchy Processing approach.

A. Four selected rehabilitation ingredients (child practice, other management of child’s body structure and function, family emotional support and addressing the professional attitudinal environment in the community through advocacy) are presented in all six pairwise combinations (first with second, first with third, first with fourth; second with third, second with fourth; third with fourth) and raters are asked to estimate the relative emphasis within each pair in the training programme they are observing on a visual analogue scale (marked with crosses). A cross in the midline indicates they are present to an equal degree. A cross on the extreme left hand side indicates the left item is emphasised to a much greater degree than the right-side item. In this particular example all crosses are to the left of midline so as it happens the left side item has been considered more important than the right but this need not be the case.

B. The relative dominance of each item pair (indicated by the red crosses) is expressed as a weight (w) conventionally ranging from 1 (equipoise) to 9 (highest possible preference/dominance) and entered into a matrix. The entries for the first row show that child

practice is considered more important than other management by a weight of 3 (i.e. moderately more important) but very much more important than family emotional support (weight of 9) and community advocacy (weight of 5). Note that the entries on the diagonal are all ones (any item is as important as itself); and that for any cell x,y with weight w , its reciprocal (cell y,x) has an entry $1/w$. Thus the weight of community advocacy “over” child practice is $1/5$ or 0.2 .

C. The matrix is analysed according to the AHP algorithm¹² and a *priority vector* showing the relative emphases of the items implicit in the judgements made in A are extracted: (specifically, the priority vector is the principle eigenvector of the matrix). A *consistency ratio* is also generated which should be low ($<10\%$) if the judgements in A are internally consistent. If need be these can then be revised.

Figure 2. Inter rater reliability and PRISM

TOP. Examples of inter-rater reliability plots. Data for three children (NCL1, TCT1 and TCT2) are shown. In each the box-and-whisker shows the range and median score for raters’ AHP-derived proportion of each of the up to 11 available ingredients. For further details see text.

BOTTOM. PRISM profiles for six TCT children. The bars show the median proportions (across raters) of the selected rehabilitation ingredients for each of six children (only eight of the eleven available options were used). Note that because these are combined medians across raters, proportions here do not add exactly to one.

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Table 1. Ingredients-Mediators matrix. For the relevance of the “yes” and “no” entries, see Methods.

	Child activity and function	Family	Physical environment	Attitudinal environment
Skill acquisition through supported practice and repetition (“learning by doing”)	yes	yes	no	no
Knowledge acquisition through education (“explicit learning”)	yes	yes	no	yes
Other management of body structure and function	yes	no	no	no
Emotional health support	yes	yes	no	no
Adaptation	no	yes*	yes*	yes

Table 2. Therapy needs item from Rehabilitation Complexity Scale ¹⁵

Number of actively-involved therapy disciplines	0	
	1	
	2-3	

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	4-5	
	≥ 6	
Therapy intensity	0	No therapy intervention
	1	Less than daily (assessment, review, maintenance, supervision)
	2	Daily sessions (5 days/week) 2-3 hours per day
	3	Daily sessions (5 days/week) >3 hours per day or approximately 25-30 hours per week)
	4	Total 1:1 therapy >30 hrs/week)

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Figure 1. Illustration of Analytic Hierarchy Processing approach

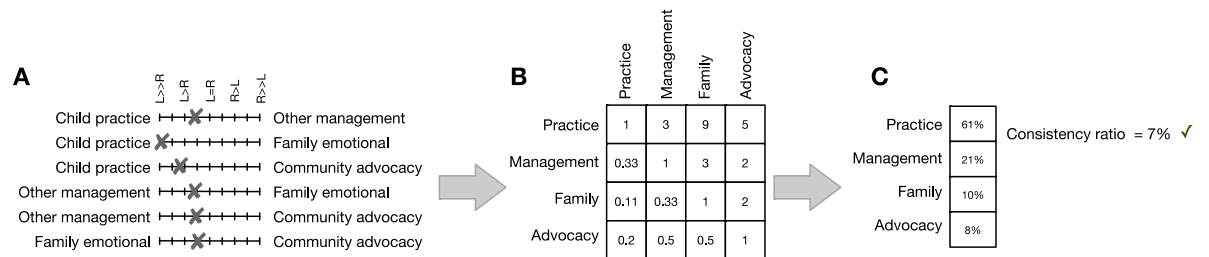


Figure 2. Inter rater reliability and PRISM profiles

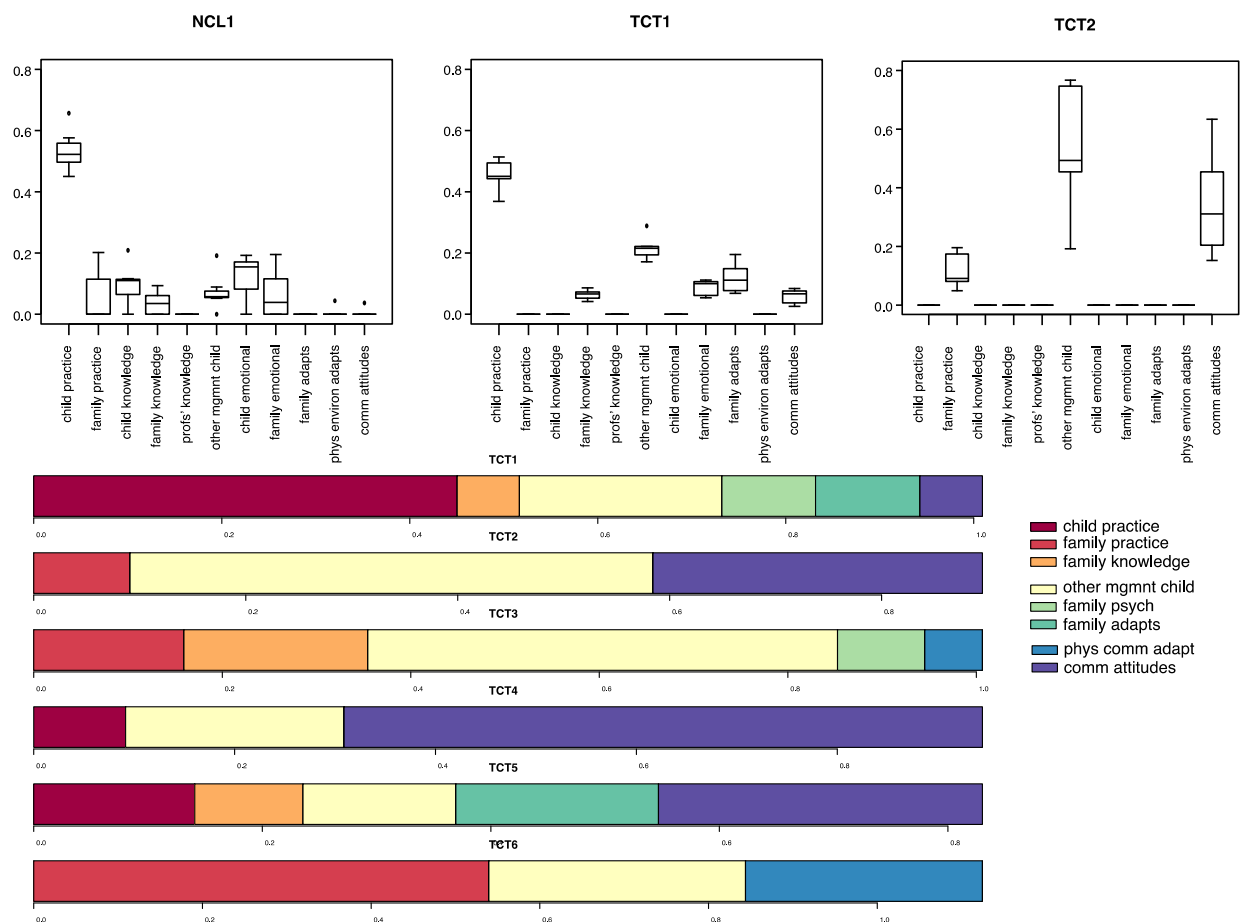
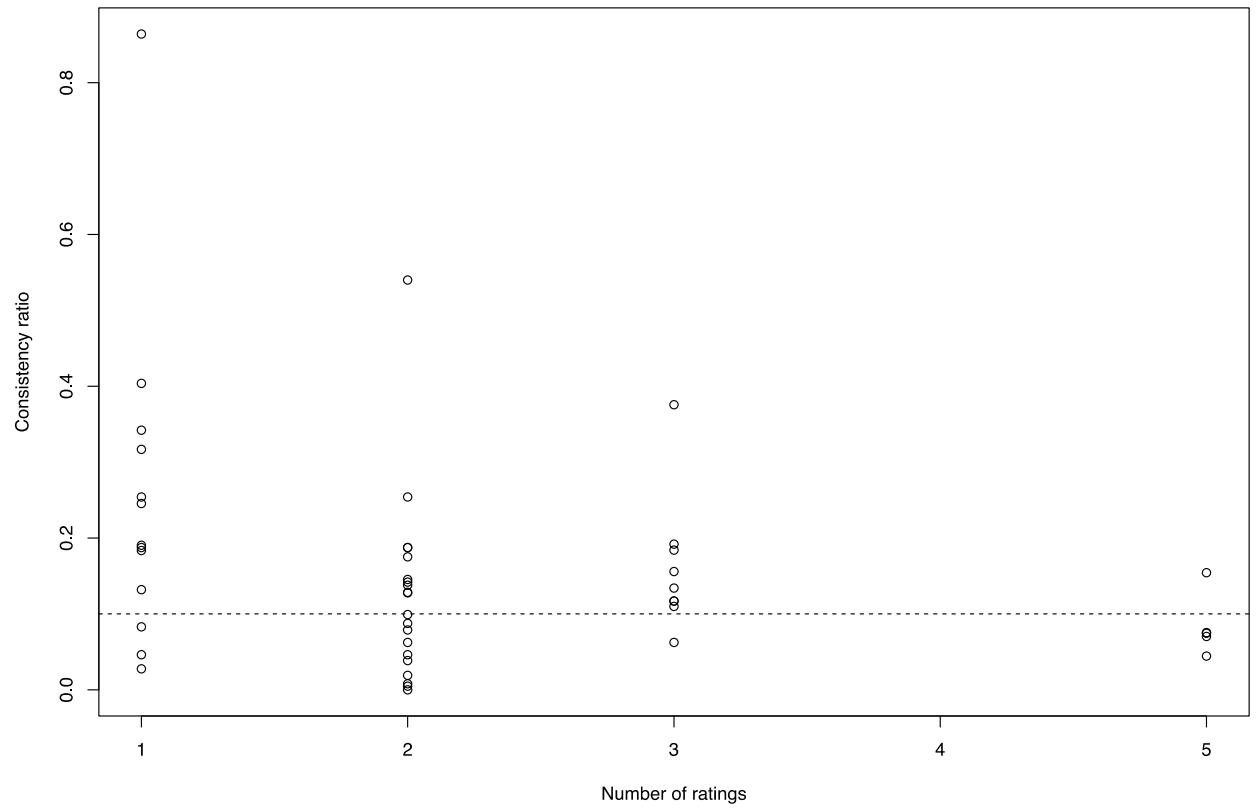


Figure 3. Effect of practice on Consistency Ratio (Supplemental material)



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